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ABSTRACT

The eight issues of Handi Helps presented in this document focus on specific issues of concern to the disabled, parents, and those working with the disabled. The two-page handi help fact sheets focus on the following topics: child abuse, leukemia, arthritis, Tourette Syndrome, hemophilia, the puppet program "Meet the New Kids on the Block" and dog guides. Each handi help provides basic information such as cause, diagnosis, symptoms, and treatment (in the case of diseases), specific suggestions for readers, and additional resources (such as organizations, books, and films). Brief informational items include use of puppets to teach children about handicaps, the decade of disabled persons, and guidelines for organizing a horseback riding program for disabled persons. (DB)

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handi helps

January 1984

FC190913



Cooperative Extension Service

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January, 1984

MEET THE NEW KIDS ON THE BLOCK

A \$30,000 grant from the Colorado Department of Education is financially supporting the educational program MEET THE NEW KIDS ON THE BLOCK for another year, in cooperation with the Colorado State University Extension Service.

The original program which teaches children about deafness, blindness, cerebral palsy, mental retardation and learning disabilities and assists positively with the mainstreaming process in our schools, 4-H clubs, and other groups will be available as well as an all new follow-up program.

A grant from the Gannett Foundation and funds from the Colorado Department of Education has enabled six new puppets to be added to the existing troupe.

This new program will reinforce what children learned in the first presentation and teach them about spina bifida, epilepsy, emotional problems, child abuse and provide insight into cultural differences and adolescent problems.

The new characters that will be doing the teaching include: Valerie Perkins, Joanne Spinoza, Stephen Arthurs, Brian McDaniel, Nguyen Huy Nam, and Jimmy Randolph (all life size puppets).

To date over 35,000 individuals have seen the presentation. We look forward to presenting the original and the all new program to thousands more and making our contribution during the Decade of Disabled Persons.

Students who will be assisting me this semester with the NEW KIDS ON THE BLOCK program are:

Mona Oversteg--CSU student majoring in occupational therapy

Kimberly Voss--CSU student majoring in occupational therapy

Russell Webber--Poudre High School junior and 4-H member

Lori Wells--CSU student majoring in human development

DECADE OF DISABLED PERSONS

The United Nations General Assembly has proclaimed the period 1983-1992 as the Decade of Disabled Persons.

The Decade of Disabled Persons is designed to carry forward the impetus given by the International Year of Disabled Persons in 1981 and the National Year of Disabled Persons in 1982.

The U.N. Declaration calls for a world wide effort to help the 500 million persons with disabilities realize their rights in leading useful and meaningful lives, to



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help with the prevention of disability and to assist with the equalization of opportunities for individuals with disabilities, as well as their habilitation in society.

However, according to U.N. Secretary-General Perez De Cuellar, the goals can only be achieved if society changes its attitude towards people with disabilities and we focus on their abilities and the contribution they can make. He states that, "We bear the responsibility to encourage and assist disabled persons to lead useful and meaningful lives. This is not to be done as an act of charity but because it is their right and because society as a whole can progress only if each of its members is given full recognition and respect for his or her own inherent dignity and worth."

The U.S. Congress, federal agencies, governors, mayors and national and local organizations are issuing proclamations and resolutions and are initiating programs. Think of what you and the groups and organizations you belong to can do and then make a commitment to follow through on your ideas.

The Eastman Kodak Company and Westinghouse Electric Corporation are making available a series of six 18" x 24" posters depicting individuals who experience disabilities achieving full participation in their own areas of interest. One poster each will be available free of charge to interested individuals and organizations. Contact: National Organization on Disability, 2100 Pennsylvania Ave., N.W., Suite 232, Washington, D.C. 20037, (202) 293-5960.

GUIDELINES FOR ORGANIZING A HORSEBACK RIDING PROGRAM FOR INDIVIDUALS WITH DISABILITIES (Bulletin 518A)

This new manual outlines the riding program for persons with disabilities conducted by Larimer County Extension Service in cooperation with the State

4-H office and the department of animal sciences at Colorado State University. It provides information from other qualified sources as well.

It was written to assist other counties interested in starting a riding program of their own. The manual provides a step-by-step description of how a successful program can be facilitated.

The publication was researched, developed and adapted by Ginger Rich, Ph.D.; Pauline Odegard-Johnson, M.S.; Laurie Kowalsky, CSU student and 4-H leader; and Rexann Story, CSU student and 4-H leader.

Cost of the publication is: \$3.25
+ .75 postage
\$4.00 TOTAL

Copies are available from:

CSU Bulletin Room
171 Aylesworth Hall, S.W.
Colorado State University
Fort Collins, Colorado 80523

FUTURE HANDI HELPS

Upcoming issues of HANDI HELPS to look forward to include:

Child Abuse

Early Education for Handicapped Children

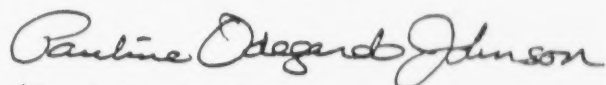
Tourette Syndrome

Chronically Ill Children

Leukemia in Children

Arthritis in Children

"Taming the Classroom Tornado"



(Mrs.) Pauline Odegard-Johnson, M.S.
Handicapped Programs Coordinator

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February 1984

CHILD ABUSE

In our visits to over 300 schools statewide, giving the educational program "MEET THE NEW KIDS ON THE BLOCK", child abuse has been mentioned by principals, teachers, physical therapists and school nurses as a serious problem their elementary school students are having to deal with.

The child abuse that is being observed includes physical, verbal, sexual, as well as neglect. The consequences of this abuse can produce physical, mental, psychological and/or emotional handicapping conditions which can lead to difficulties with school performance and learning.

This issue of Handi Helps addresses child abuse and will provide basic information on the topic and give suggestions to those working with children who are or are suspected of being abused.

GENERAL INFORMATION

Physical child abuse is a major cause of death in children. In 1979, the U.S. had 700,000 reported cases, with about 2000 of these cases resulting in death. Many incidents go unreported.

Verbal abuse is very common and ranges from mild cases of cursing and belittling, that temporarily upsets a child, to extreme cases that can affect a child's mental health. There are no specific figures concerning verbal abuse.

With sexual abuse, 50% of the cases occur in girls under the age of 12 years.

Neglect is usually easy to detect. The child may dress in unusually dirty clothes, smell badly, or be malnourished. Neglect also includes the child being left alone to care for him/herself.

Generally, the majority of child abuse cases occur in children under the age of three.

CHARACTERISTICS OF THE ABUSER

Abusers come from every occupation and every economic class, they cross all racial and age lines. In 90% of the cases, the child abuser is a related caretaker of the child. Often, the abuser was abused or neglected as a child him/herself. Additionally, the abuser is usually the person who spends the most time with the child.

Several factors may influence a parents tendency to abuse their child. Among these are high stress situations, such as losing a job; having extremely high expectations of the child and the child is unable to meet these expectations; and believing that beatings are an effective means of disciplining.

Frequently the abuser hates what he/she does to the child, but doesn't know how to stop. Because child abuse carries a lot of stigma, abusers have difficulty admitting the need for help and thus seeking it. Also adding to the difficulty of seeking help is the fear that his/her children will be taken away. Most parents do love their abused children.

EFFECTS OF ABUSE ON THE CHILD

According to Nina Wentz, director of Child Abuse Resource and Education Inc., in Greeley, sexually abused children exhibit symptoms such as becoming distant and un-
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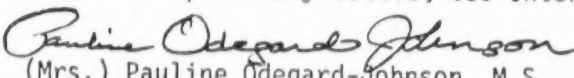


communicative, having a fear of going to bed, having a fear of sleeping alone, having nightmares, wetting the bed, changing relationships with friends, becoming rebellious, becoming a loner, appearing to need more reassurance than usual, clinging to a parent, skipping school, running away, losing his/her appetite, being irritable, and developing a short temper.

Possible signs for other types of abuse include being aggressive at school, often fighting with other children and bullying them around; being afraid to go home after school or arriving at school very early before it even opens; being overly shy and fearful of adults; and having a short attention span in school.

WARNING: Remember, because a child exhibits some of the above signs, this does not necessarily mean the child is abused.

HANDI HELPS

1. If a child comes to school or a 4-H club meeting, etc. repeatedly with bruises and marks on his/her legs, arms and face, the school principal, 4-H leader, etc. should report the case to a child protective agency within 24 hours of detecting the abuse. The agency should become involved before injuries disappear. This agency provides support to the family so their stress can be reduced or they can learn to better cope with it.
 2. If the child is physically in danger, call the police. They are the only ones who have the authority to take the child away from the caretakers. The child would then be placed in a protective home.
 3. Children may come to school or extra curricular activities in long sleeved clothes, even during hot weather. This may be an indicator of an attempt to cover up the marks and bruises from beatings.
 4. A teacher, school nurse, school counselor, 4-H leader etc. may be the only one a child will open up to about his/her problems at home. If you suspect child abuse, talk to the child in a private setting by asking him/her about things at home.
 5. The school nurse can be asked to look at a child who is often bruised. She can decide if the marks and bruises are accidental or inflicted.
 6. When a child is having emotional problems in school and trouble with his/her school work, emotional abuse and neglect may be suspected. Refer the parents/guardians to a mental health service for counseling. If no action is taken by the caretakers of the child, report the case to the child protective agency.
 7. Siblings of abused children should be evaluated by the school system to see if they have also been abused.
 8. Do not reprimand parents or guardians for their abusive behavior. Leave this up to the child protective agency. The caretakers may feel as if the child has "told on them" and therefore the child deserves additional beatings.
 9. Abusive parents feel as if no one is giving them support when they are having a problem. Friends of these parents should pay attention to the problems they are having and help them with their child rearing, perhaps by offering to babysit during stressful times. Support groups of parents who abuse their children can also be helpful, e.g. Parents Support Anonymous, which borrows many aspects from Alcoholics Anonymous.
 10. In all 50 states the law protects reporters of child abuse against legal suits from the abusing parents/guardians.
- This information was obtained primarily from the C. Henry Kempe National Center for the Prevention and Treatment of Child Abuse and Neglect, 1205 Oneida Street, Denver, Colorado 80220 and was compiled with the help of Mary Cottle, CSU Intern.
- 
(Mrs.) Pauline Odegard-Johnson, M.S.
Handicapped Programs Coordinator

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March 1984

LEUKEMIA

Leukemia is a disease which affects the blood producing tissues of the body, causing the overproduction of non-functioning white blood cells. The abnormal white blood cells cause other abnormal body conditions: anemia, excessive bleeding and bruising, and infections. Although leukemia is the leading cause of disease related death in children, most cases occur in people over 40 years of age. The "acute" or rapidly progressing type of leukemia most often occurs in children, while the "chronic" or slower progressing type most often occurs in adults. This year nearly 62,000 Americans will develop leukemia and other blood diseases; 4,000 of these cases involve children.

CAUSES

The actual cause of leukemia is not yet known, although it is known that it is not contagious or inherited. Generally, it is believed that a change in genetic structure causes the overproduction of abnormal white blood cells. Studies have indicated that several factors may contribute to the change in genetic structure. These factors include excessive exposure to radiation, X-rays, and chemicals such as benzene. Also birth defects such as Down's syndrome and some viruses have been associated with leukemia.

SYMPTOMS

There are several symptoms of leukemia,

some of which may be associated with more common ailments, such as the common cold. These symptoms are:

1. Anemia. This is a condition in which the red blood cell count is much lower than normal. A pale complexion may result.
2. Weakness and fatigue. These are due to the individual's anemia.
3. Excessive nosebleeds and bruising. These are caused by the inability of the blood to clot. This is because the normal production of platelets which regulate coagulation and bleeding is inhibited by leukemia.
4. Persistent high fever, pain in the bones and joints, and swelling of the lymph glands, liver and spleen.
5. Re-occurring infections. These infections are caused by the malfunctioning immunity system.

It is important that a child is taken to the doctor if any of the above symptoms persist or occur often.

TREATMENT

It is important that the treatment of leukemia begin as soon as possible after it is diagnosed.

The initial treatment of leukemia is done using chemotherapy. This is when powerful drugs are given to kill off abnormal cells and slow down their reproduction. Leukemia has periods of activity and inactivity. When the disease is active, blood transfusions, bone marrow transplants and antibiotics



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may be used as part of the treatment. In some cases, radiation is used to help rid the body of any active leukemic blood cells.

The latest information from the medical profession indicates that remission (disappearance of symptoms--5 years plus) is now achieved in 50 to 90 percent of today's leukemia cases.

HANDI HELPS

1. Communication between the school, home and hospital is important in order to maximize the potential for success that a child with leukemia has in school.
2. As with other diseases, a child with leukemia may miss a great deal of school. Once the child is back in school he/she may need some extra help or tutoring to catch up. Make these adjustments as positive as possible and assist with arrangements where necessary/possible.
3. A child with leukemia should be treated as much like other children in school as possible. Treating the child as a student and not as a patient will allow him/her time to think of things other than the illness.
4. Do not overprotect the child with leukemia. The doctor will set limits that are appropriate and further limiting the child's behavior is unnecessary.
5. Children with leukemia may try to manipulate adults by using their illness as an excuse to get their way. It is important to set rules and stick to them.
6. Allow the child with leukemia to explain his/her disease with other children in the school. This enables the child to retain control of the situation without feeling as though people are talking behind their back.
7. A child undergoing chemotherapy may lose his/her hair. This can be

very distressful for a school age child because of the importance placed on peer relationships and body image. Help the child to think positively about the situation.

8. Allow the child to discuss his/her feelings with you. It can be a great relief for them to have a sympathetic ear nearby.
9. Plan to do some special things with the child when he/she is feeling very frustrated about being sick so often. Giving flowers to the child or fixing their favorite meal may brighten up the day a bit.
10. Remember to give support to parents and siblings of the sick child. All illnesses that require a lot of attention and special treatment can be very draining on the rest of the family. Problems may develop between a husband and wife, and children may feel left out or neglected because of all the attention their brother or sister is receiving.

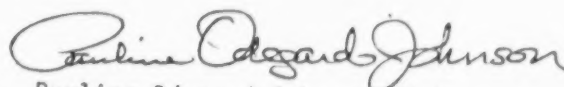
RESOURCES

Information in this newsletter was taken from publications made available by the Leukemia Society of America.

For more information contact:

Leukemia Society of America, Inc.
National Headquarters
800 Second Avenue
New York, NY 10017
(212) 573-8484

Colorado Chapter
601 Broadway, #217
Denver, Colorado 80203
(303) 572-3000



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Handicapped Programs Coordinator

(Compiled with the assistance of
Mary Cottle, Student Intern, CSU)

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April 1984

ARTHRITIS

Arthritis is the number one crippling disease in the U.S. today, affecting over 30 million people, including over 250,000 children. The word arthritis literally means inflammation of a joint. The term arthritis is used to cover close to 100 different conditions which cause aching and pain in joints and connective tissues throughout the body, not all of them necessarily involving inflammation. The actual causes of arthritis are not known. It can strike anyone from the very young to the very old--and there is no cure.

CLASSIFICATION

The five most common kinds of arthritis are:

- 1) Rheumatoid arthritis. This is the most serious, the most painful and most potentially crippling. It can affect the whole body. It primarily attacks the joints, but can also cause damage to the lungs, skin, blood vessels, muscles, spleen, and heart. It tends to subside and flare up unpredictably, often causing progressive damage to tissues. Women are affected three times more often than men.

In children it occurs in a form known as Juvenile rheumatoid arthritis and sometimes can be quite serious.

- 2) Osteoarthritis. Also called degenerative joint disease, this is usually a mild disease and is not generally inflammatory. It does not cause general illness or affect parts of the body other than the joints. Mild to severe disability may develop gradually.
- 3) Ankylosing spondylitis. This is chronic inflammatory arthritis of the spine. It usually begins in the teens or early twenties.
- 4) Systemic lupus erythematosus. Called "SLE" or "LUPUS", for short, this is an acute systemic disease which can inflame and damage joints and organs throughout the body, including the kidneys, heart, lungs, brain, and bloodvessels. A skin rash on the face is common. It strikes women more often than men.
- 5) Gout. This disease is, in many cases, but not always, an inherited disease. It can attack and inflame any of the joints, usually one at a time, and especially the big toe. Most victims are men. It is intensely painful.

TREATMENT

Treatment for arthritis may include any one or all of the following: medication, rest, exercise, posture rules, surgery, and rehabilitation.



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Aspirin is the most frequently prescribed anti-inflammatory drug, because it reduces inflammation as well as pain. The aspirin must be taken in large doses regularly, day after day, even during periods when pain and swelling have subsided and the patient is feeling better. Because people vary in their tolerance for aspirin, it should be taken for arthritis only as prescribed by and under the supervision of a physician.

JUVENILE RHEUMATOID ARTHRITIS (JRA)

This disease usually occurs between age six months and one year and most always before age seven. Seventy percent of its victims outgrow the disease, 20% will have mild effects and 10% carry it to adult age. In most children the disease process begins gradually with arthritis that usually affects the knees. Frequently it is painless and without the morning stiffness that is experienced with adult rheumatoid arthritis. Some children have the disease in one joint only. The disease may also begin with a high fever which can reach 105 degrees. The fever is accompanied by a measles-like rash that may last for weeks or even months. This disease may retard normal growth and development during adolescence, if untreated. It may also damage internal organs or the eyes.

There is no cure for JRA, but children can be greatly helped by proper care and treatment, including the use of anti-rheumatic drugs as well as physical therapy. For the child with JRA who is given prompt, expert medical care and normal living and schooling,

along with the parents' love and reassurance, the outlook is very favorable. The disease often has a spontaneous remission and leaves little or no permanent damage.

HANDI HELPS

1. Help the child to follow his/her rest, exercise, and medication schedules. These schedules are important in arresting this crippling and painful disease.
2. Provide emotional support without being over protective. Lend support to the child while helping to maintain a normal as possible lifestyle.
3. Realize that arthritis is a disease which may be worse on certain days or weeks than others. On bad days the child may appear irritable and fatigued. Emotional support during these times is extremely important.

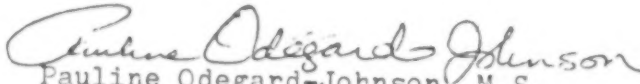
RESOURCES

The information in this newsletter was obtained from the Arthritis Foundation.

Rocky Mountain Chapter
234 Columbine St., Suite #210
Denver, CO 80206
(303) 399-5065

American Juvenile Arthritis
Organization (AJAO), Arthritis
Foundation
3400 Peachtree Road, N.E.
Atlanta, GA 30326

This issue of HANDI HELPS was prepared by Betsy Cook, Senior in Psychology, C.S.U.


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May 1984

TOURETTE SYNDROME (T.S.) Multiple Tic Disorder

Tourette Syndrome is a neurological disorder characterized by involuntary muscular movements, uncontrollable vocal sounds and in approximately 60% of the cases the use of obscene words.

The disease is named for Gilles de la Tourette, a French doctor who first described it in 1885.

Tourette Syndrome usually begins in childhood, between the ages of two and sixteen, and is three times more common in boys than in girls.

The syndrome is generally lifelong, but it is not a degenerative or fatal disease. Individuals with T.S. can expect to live a normal life span. In a handful of cases, complete remission occurs after adolescence.

Everyone with the disease starts with tics (short, rapid, uncontrolled movements). The tics may vary from one to thousands per hour in frequency. No two individuals with Tourettes are alike. Usually the tics are increased during stress and reduced when the person is not anxious or is deeply involved in an activity; often the tics disappear during sleep.

SYMPTOMS

A facial tic, often the blinking of both eyes, is likely to be the first symptom.

Other symptoms of Tourette Syndrome can include one or more of the following, depending of the severity of the case: twitching of nose, grimacing of face, sniffing, jerking of the head, arm or leg, turning in circles, hissing, barking, snorting, grunting, clucking, growling, throat clearing, repeating phrases, uncontrollable uttering of obscenities (coprolalia), repeating the words of others (echolalia), banging of one's head against hard objects, and many others.

The tics and movements of Tourette change (wax and wane) every few months with new ones replacing or being added to the old ones. This can be confusing to parents/teachers and they may think the child is intentionally causing the tics for attention or is acting out. A person with Tourette Syndrome can't stop their unusual and excessive extra movements.

It should be remembered that just because a person has a tic, this does not mean he/she has Tourette Syndrome; however, it must be considered as a possibility anytime there are multiple tics with vocalizations.

CAUSE

No one knows for sure what causes T.S.; many believe it is a chemical malfunction in the central nervous system, which regulates movement and behavior.

DIAGNOSIS

Because T.S. is relatively rare and so little is known about the syndrome, most doctors have never seen an actual case. Only recently are most doctors able to recognize T.S. when they see it.



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A full 80% of all newly diagnosed patients come to their doctors having diagnosed themselves after reading an article or viewing a TV program about T.S.

Frequently individuals who have T.S. are misdiagnosed and go untreated. It is most often misdiagnosed as an emotional problem, which it is not. Other misdiagnoses include: hyperactivity, learning disability, and epilepsy.

People have been known to have T.S. for 10 to 12 years before they discovered the real cause of their tics. Some never do. It is estimated that there are 50,000 to 100,000 people in the country who have Tourette Syndrome and do not know what their disability is.

Early diagnosis is so important so the ridicule, teasing and rejection from others can be minimized or better yet eliminated.

TREATMENT

Today, Haldol is a medication that is often prescribed to help control the symptoms. It is given in very small doses that are increased slowly until the best possible balance between symptoms and side effects is achieved. The relief is usually only partial and there are side effects. Short term side effects include: restlessness, drowsiness, irritability, depression, paranoid reactions (e.g. to school), itching, swelling, sensitivity to bright lights, difficulty with short term memory and many others. Long term side effects are not known.

The person with T.S. also spends much time and energy trying to control their symptoms on their own, which some can do for very short periods of time, but eventually the inhibition causes an explosive build-up of other symptoms.

Other methods of treatment that have been tried in the past have included: psychotherapy, vitamin therapy and hypnosis.

HANDI HELPS

Individuals with T.S. have the same needs for companionship and acceptance as anyone else; look at the whole individual, not just the disease.

The major goal when working with a child who has T.S. should be the development of the child's self-concept. Provide as many opportunities as possible so the child can feel good about him/herself.

Show the child acceptance and respect and be a good role model for the others in the group. Teachers/adults can dramatically affect the lives of their students/4-Hers/others with T.S. in how they handle the situation.

Teachers/others should be aware and knowledgeable about this syndrome and share their information with other educators, because they can play an important role in identifying students who may unknowingly have Tourette Syndrome and by then referring them to the proper professionals.

Teachers/others should also share the information they have about T.S. with the peers of children with Tourette Syndrome because it can be the beginning of acceptance and help the individual with T.S. avoid the social isolation they so frequently experience.

Praise the child with T.S. for things one might take for granted with other children. Stress the positive, not the negative; for example, tell the number he/she got correct on a test rather than the number wrong.

Parents and teachers should maintain constant communication. Parents can also be good resources to those who want to learn more about T.S.

People with T.S. have IQs in the same range as the average population. They must not be considered dull or lazy. People with T.S. have become doctors, lawyers, teachers, musicians and scientists. One of the most famous persons who had T.S. was Samuel Johnson, who wrote the first English dictionary. Approximately 50% may have some learning disabilities and have difficulty with

time, space and directionality. But remember the child with T.S. can learn. If they can't learn the way we teach them, then we must teach them the way they can learn.

Give clear directions and make sure the student with T.S. understands what is expected.

Many children with T.S. have poor handwriting. Be flexible and allow alternatives to writing; for example, give tests orally, let the student use a tape recorder to record lectures and do one's work, let the student type or print on lined paper, allow a peer to make a carbon copy of their notes for the student with T.S. or arrange for a tutor.

Give the child with T.S. recorded books, so he/she can listen to books rather than read them if he/she cannot read quickly, because he/she gets stuck on words.

Give the student with T.S. his/her tests in short segments with rest periods inbetween those segments. Allow extra time to finish homework and tests.

Allow him/her to take their test in a separate room if that arrangement will help eliminate distractions.

Avoid abrupt changes from one activity to another. Inform the students that in five minutes they will be going on to another activity.

Students should have the opportunity to get up and walk around. Send them on errands. Provide a place for them to go if tics become intensified; for example, the nurse's office, the resource room--some private area where he/she can express his/her tics and not be seen by others.

FUTURE

Research on T.S. is being done at the National Institute of Neurological and Communicative Disorders and Stroke, the National Institute of Mental Health and major private medical institutions to find new drugs that might help individuals with T.S., to conduct genetic studies, etc.

RESOURCES

Tourette Syndrome Assoc., Inc.
41-02 Bell Boulevard
Bayside, New York 11361
(212) 224-2999

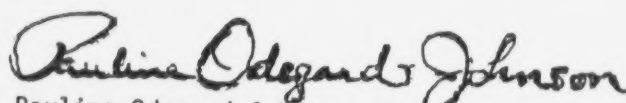
Films: "Stop It! I Can't!"

A film for children about T.S.
Contact: Tourette Syndrome Assoc.

Tourette Syndrome: The Sudden Intruder

Contact: Behavioral Sciences Media
Laboratory, Neuropsychiatric
Institute, UCLA, 760 Westwood
Plaza, Los Angeles, CA 90024
(213) 825-0448

Sources of information for this issue of HANDI HELPS include: Sandy Swain, founder of the Fort Collins, Colorado chapter of the Tourette Syndrome Assoc., Inc. and the Tourette Syndrome Assoc., Inc., NY.



Pauline Odegard-Johnson, M.S.
Handicapped Programs Coordinator

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Cooperative Extension Service

Colorado State University
Fort Collins, Colorado 80523

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handi helps

September 1984

HEMOPHILIA

Hemophilia is a hereditary blood clotting disorder.

Teachers/4-H leaders/others who have not had recent experience with hemophilia usually feel very anxious about having someone with hemophilia in their class/group. They fear that the individual will bleed severely after a small cut or bump.

People with hemophilia do not bleed any faster or harder than anyone else. Instead their bleeding is prolonged or they have delayed oozing. And even when a clot does form it is soft and mushy and is not effective.

CAUSE

An absence of one of the ten clotting factors or proteins in the blood is the cause of hemophilia. It is transmitted from mother to son in almost all cases. Approximately one in every 10,000 boys are born with hemophilia. All races and socioeconomic groups are affected equally. Females may be carriers of the disorder but seldom have bleeding problems themselves. Very rarely a female will be born with hemophilia if her mother is a carrier and her father has hemophilia.

DIAGNOSIS

Laboratory studies are required for diagnosis. A woman can be tested to see if she is a carrier by having a blood test. Prenatal diagnosis can be made through amniocentesis.

SYMPTOMS

There are different types of hemophilia and three levels of severity.

Mild. There is prolonged bleeding only with surgery, tooth extractions or major injuries. These children seldom have playground injuries requiring special medical treatment.

Moderate. Bleeding can occur into joints or muscles following relatively minor trauma, such as a sprain or bump.

Severe. Bleeding episodes are more frequent because individuals may have bleeding into joints, muscles or body organs with no apparent injury or cause as well as prolonged bleeding with trauma or surgery.

TREATMENT

There is no cure for hemophilia; however, bleeding is readily controlled with current medical treatment.

The majority of bleeding episodes will involve internal bleeding into joints or muscles. Repeated bleeding into joints causes a type of arthritis and muscle weakness will occur adjacent to the affected joints. Bleeding into muscles can put pressure on nerves causing pain, numbness and temporary inability to move the affected areas.

Immediate treatment is important and will limit the pain and allow the individual to resume normal activities more rapidly. Early treatment also promotes reabsorption of the blood by the body more quickly.

Intravenous infusion of the missing clotting factor is given. The procedure takes approximately 10 to 20 minutes. Many youth or their parents have learned to give the intra-



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venous infusions at home. This is more convenient, allows earlier treatment and decreases time missed from school.

HANDI HELPS

1. Youth who have hemophilia are taught how to avoid trauma, manage minor bleeding and recognize bleeding that requires immediate medical intervention.
2. Be sure to listen to the individual with hemophilia. They can recognize the early signs of bleeding before they are obvious to teachers/parents. Teacher/parent observations are important in detecting bleeding in very young children e.g. limping, not using a limb, etc.
3. First-aid treatment is the same for a person with hemophilia as it is for anyone else.
4. Notify parents/doctor immediately after even a minor injury, but especially after injury to the head, neck or chest. All head injuries are to be considered serious because of the danger of brain hemorrhage. Neck injuries are serious because of the potential problems of an obstructed airway. Injuries to the abdomen/chest can be serious because of possible injury to internal organs.
5. Never give an individual with hemophilia aspirin. It can aggravate his/her tendency to bleed.
6. Safety measures that are appropriate for all young children are generally sufficient for those children who have hemophilia. Avoid repeated cautions to "be careful."
7. Some bleeding will occur despite all precautions and there is no such thing as a perfectly safe environment.
8. The majority of students with hemophilia can engage in many normal physical activities. Moderate exercise is essential because strong muscles protect joints and decrease the frequency and severity of bleeding episodes. Also exercise is important for normal motor development. Rough contact sports like football should be avoided; swimming is a good activity.
9. A public announcement to the rest of the class/group that a child has hemophilia is not appropriate. This is an invasion of the student's privacy and may result in the other classmates avoiding or teasing him/her.
10. When peers have questions about hemophilia, adults can help the child decide what to say, but should not answer for them. If the student with hemophilia volunteers to share information with other students, this can be very effective.
11. Don't give preferential treatment to the child with hemophilia. This could interfere with the normal social development of the individual.
12. Efforts to normalize the school experience are vital to the youth's education and self image, so he/she does not feel different or inferior.
13. Life expectancy is normal for a person with hemophilia. Teachers/others should assist them in exploring careers that don't involve heavy manual labor. Careers that can be considered include those in the areas of: professional, scientific, technical, managerial and clerical.

RESOURCES

Mountain States Regional Hemophilia Center
University of Colo. Health Sciences Center
4200 E. Ninth Avenue
Denver, Colorado 80262
(303) 333-5122
(Has speakers that go out to schools/etc., has excellent materials, serves as a multi-disciplinary comprehensive evaluation center. They are the source of information for this issue of Handi Helps.)

National Hemophilia Foundation
19 W. 34th St., Suite 1204
New York, N.Y. 10001
(212) 563-0211

Pauline Odegard-Johnson

Pauline Odegard-Johnson, M.S.
Handicapped Programs Coordinator

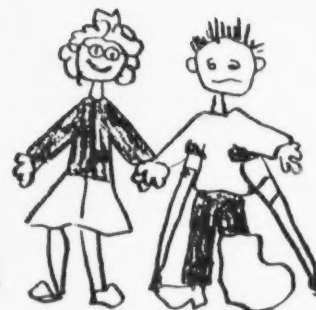
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October 1984

"MEET THE NEW KIDS ON THE BLOCK"

Colorado Department of Education (CDE) is totally funding the educational program "MEET THE NEW KIDS ON THE BLOCK" for a third year. The amount of the grant received is \$31,000. The program coordinator is grateful to CDE's continued support of and interest in the educational program which assists positively with the mainstreaming process in our schools/4-H clubs/etc.

The program is presented in cooperation with the CSU Cooperative Extension Service, which makes in-kind contributions.

SERVICES AVAILABLE:

1. This grant makes possible the presentation of the original Kids on the Block presentation which teaches elementary children about deafness, blindness, mental retardation, learning disabilities and cerebral palsy.

2. If your group/school enjoyed the original program, you may be interested in requesting the all new follow-up program. Stars of the follow-up presentation include five new puppets. Valerie Perkins teaches children about spina bifida; Brian McDaniel who has epilepsy shares with his friend what to do if he has a seizure; Jimmy Randolph has emotional problems and Stephen Arthurs talks about child abuse. The two nonhandicapped puppets, Joanne Spinoza and Nguyen Huy Nam, provide insight into adolescent problems and cultural differences respectively.

The new program is based on the same format as the original one and is appropriate for elementary school children. The length of the program remains approximately 50 minutes and children once again have the opportunity to ask the puppets questions about the disabilities presented.

As before there is no charge for the program; however, if a school/PTO/other would like to make a contribution to the program we will accept it.

If your school/group is interested in seeing this new program, please contact me to make arrangements.

3. "What's It Like"? is a 60 page activity manual that is being presented to groups after they see the puppet shows. I designed the publication to reinforce the goals/purposes of the Kids on the Block programs. The manual can be used as a supplement or it can stand on its own. The manual provides teachers/4-H leaders/others with simulation activities, discussion topics, potential speakers, written activities, games and skill development projects that youth/adults can participate in to gain a better understanding of people who have disabilities. There is also a glossary of terms, background information about various disabilities and statewide agencies that can be of assistance.

The manual will be helpful to those organizing handicapped awareness days/weeks, planning curriculums regarding people with disabilities, sensitizing others about their peers who have disabilities, etc.



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Funds to develop and print the manual were made possible by the grant from the Colorado Department of Education, utilizing P.L. 94-142, Title VI-B funds. Copies are available by writing me; there is no charge for the publication.

4. Handi Helps, a monthly newsletter about disabilities, will continue to be available during the school year. If you have just been added to the mailing list, back issues are available. Topics of back issues include: visually impaired, deaf and hearing impaired, mental retardation, learning disabilities, cerebral palsy, epilepsy, autism, giftedness, spina bifida, community resources that can help one work with the handicapped, diabetes, children's literature that deals with various disabilities, recreational/sport opportunities for individuals with disabilities, wheelchairs, publications for parents of handicapped preschoolers, health care resources, shyness, a handicapped child's effect on the family, terminology, cystic fibrosis, child abuse, leukemia, arthritis, Tourette Syndrome and hemophilia.

Requests for back issues should be sent to me at the mailing address on the front of this newsletter. There is no charge for the newsletter or the back issues.

OTHER MATERIALS AVAILABLE:

5. Donna Brown, representing the Colorado Arabian Horse Club, recently presented a check for \$100 and miscellaneous tack for use in the Colorado 4-H handicapped horseback riding program. The money will be used to buy additional tack and equipment that is loaned by CSU to 4-H and/or horse clubs that work with the 4-H riding programs for individuals with disabilities. If you are interested in using the tack/equipment, e.g. helmets, contact me or:

Dr. Ginger Rich
CSU Extension Horse Specialist
Animal Sciences Bldg.
CSU, Ft. Collins, CO 80523

Our thanks to Donna Brown and the Arabian horse club for their contribution to and interest in this program area.

6. Along with the horse tack, a manual titled, Guidelines for Organizing a Horseback Riding Program for Individuals with Disabilities, Bulletin 518A, is available to assist those interested in organizing and facilitating a riding program. The manual provides information on: selecting an instructor, volunteers needed, funding riders, selection of horses, special equipment needed, facilities needed, insurance coverage, release forms required, program evaluation, program closure, promotion, funding and resources.

The manual sells for : \$3.75
.75 postage
\$4.00

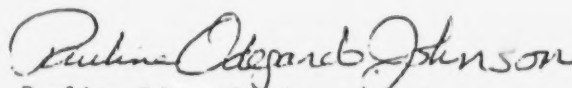
It can be ordered from:

CSU Bulletin Room
171 Aylesworth Hall, SW
Colorado State University
Fort Collins, Colorado 80523

The how-to manual was written after Dr. Rich and I completed a pilot riding program for individuals with disabilities.

RESOURCE

If you have any questions or believe I can be of assistance to you, please call.

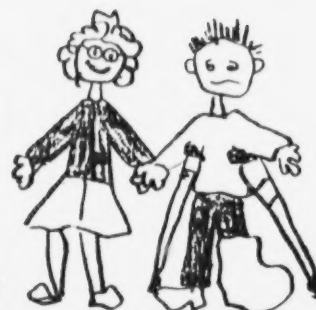

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November/December 1984

DOG GUIDES

Often times the terms "seeing eye dog" and "guide dog" are used to refer to all dogs trained to assist people who are blind. These are proper terms and refer to those dogs trained at certain centers/schools. The generic term "dog guide" should be used unless one is referring to dogs trained at a specific center. This is similar to people referring to all gelatin desserts as "Jello" when there are many brands.

Background Information. Approximately 5000 people in the U.S. and Canada use dog guides. Dog guides are not for everyone who is blind. Some individuals prefer to use a white cane; others believe dog guides provide a much greater opportunity for personal independence and faster mobility/travel.

The individual who chooses to have a dog guide must like animals, be willing to assume the responsibility that comes with having a dog and have very little or no useable vision to fully use the dog's guidance.

History. Dogs have served mankind since prehistoric times by being our pets, companions, protectors and herders. Dogs performing practical functions for people with disabilities began in the early 1920's. Following World War II, the German government began a program in which dogs were used to guide war veterans who had become blind. The program was never very successful.

Dorothy Harrison Eustis, an American breeder of German shepherds, learned of the program while living in Switzerland. With the help of Morris Franks, a 19

year old blind man from Tenn., and utilizing information from the German's program, she successfully trained her first dog guide. In 1929 they founded the Seeing Eye Inc. to provide dogs for Americans who were blind.

The Dogs. Some schools breed their own dogs, others rely on a selected pool of breeders as their source for puppies. The breed of dog selected varies from school to school. Some select only purebred German shepherds, others select golden retrievers and Labrador retrievers, still others Doberman pinschers or boxers. Mixed breeds are used as well by some.

Training. In some states, usually those located near training centers, 4-Hers and their families provide foster homes for puppies until they are old enough for admission into a training program for dog guides. The 4-Hers receive the puppy when it is about 8-12 weeks old and give it a home until it is one year. Only one dog guide puppy may be raised in a home at a time. However, the family may have other pet dogs. The 4-Her prepares the puppy for his/her future training as a dog guide by teaching the puppy basic obedience and courtesy, by housebreaking it and providing it with as many experiences as possible. The dogs are always on a leash and must have constant human companionship--they must sleep by their trainer's bed, sit by the trainer during meals--they must do everything together.

If the dog is successful in learning the above basics and meets the school's criteria for intelligence, temperament, confirmation and health the dog is accepted into a training program for several months of intensive training. If the dog does not meet the criteria, the 4-Her may keep the dog, if he/she wishes.

Once the dog is admitted to a training program, commands are worked on first--"come",



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"sit", "down". Next they learn to work in a harness and follow the commands "forward", "left", "right".

After mastering the commands the dog is tested in the real world of traffic, crowds, buses, meeting strangers, riding escalators and elevators, schools, churches, shopping centers, airports. They learn to socialize with dogs and cats. They also learn to stop at curbs, judge the flow of traffic and safely avoid obstacles.

If the dog does well on the previous components of training it is ready to be matched with a person who is blind and desiring a dog. The dog guide on the average is 18 months old when it is placed with its master. Depending on the policy of the school providing the dog, the blind individual is generally 16-18 years old or older. Once matched the person who is blind and the dog begin four weeks of training and orientation together in order to become a team--each knowing the other's individual habits.

During the first part of team training the team works on commands in usual situations e.g. crossing streets, walking in crowds, going shopping. The dog is trained to act only on the master's commands.

For example dog guides cannot "read" traffic signals. Rather the master waits for audio signals such as the stop of traffic or the movement of other pedestrians and then gives the dog the command to proceed. The trained dog will do so only if the street is free of moving vehicles. Also the master must know where he/she is going or must ask for directions so the dog can be directed correctly and they can work smoothly as a team. The directions may be given by hand movements and/or voice, e.g. forward may be indicated by a wave forward with the hand as well as by the word command "forward".

During the end of the four week training the team works on specifics and situations unique to the master's life.

Cost. Cost of raising and training a dog and its master ranges from \$3000 to \$8000 per dog. The dog and training is provided without charge to the recipient at most of the schools.

Schools. All total about 1000 dogs are trained per year. Some of the dog guide schools and associations that train the dogs and can be contacted for additional information follow.

The Seeing Eye, Inc.
P.O. Box 375
Morristown, NJ 07960
(201) 539-4425

Guiding Eyes for the Blind, Inc.
611 Granite Springs Road
Yorktown Heights, NY 10598
(914) 245-4024

Guide Dog Users
American Council of the Blind
1211 Connecticut Avenue, N.W.
Washington, D.C. 20036
(202) 833-1251

Pilot Dogs, Inc.
625 West Town St.
Columbus, OH 43215
(614) 221-6367

Guide Dogs for the Blind, Inc.
P.O. Box 1200
San Rafael, CA 94902
(415) 479-4000

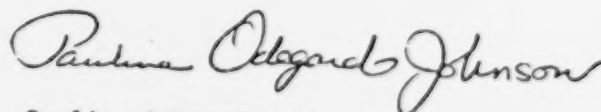
Leader Dogs for the Blind
1039 Rochester Road
Rochester, MI 48063
(313) 651-9011

Guide Dog Foundation for the Blind, Inc.
109-19 72nd Avenue
Forest Hills, NY 11375
(212) 263-4885

International Guiding Eyes, Inc.
13445 Glenoaks Blvd.
Sylmar, CA 91342
(213) 362-5834

Reminder. One should never pet, feed, talk to or call the dog guide without permission from the owner. The dog is "on duty" and disrupting him/her concentration may make the dog unreliable and thus unuseable by the person who is blind.

Resources. Information for this newsletter is from: The National 4-H Council and THE HANDICAPPED COLORADAN (Vol. 6, No. 6).



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